VIEWPOINTS

SPRING 2021

A QUARTERLY NEWSLETTER BY PARKINSON SOCIETY BRITISH COLUMBIA

Parkinson Society British Columbia

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OUR MISSION

Parkinson Society British Columbia exists to empower people with Parkinson's in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy.

YOUR SUPPORT IS ESSENTIAL

Parkinson Society BC would not exist without the support of our members, donors, and volunteers. Here are a few of the ways you can support your Society:

Membership: For an annual fee of $25, your household benefits from unlimited access to our education and support services, events, and resources.

Donations: Contact us to set up monthly, quarterly or annual donations, or think of us when giving through United Way.

Planned Giving & Bequests: Consider Parkinson Society BC as a beneficiary in your will.

Fundraising: Become a Champion for Parkinson's by organizing your own event benefiting the Society.

For more information on how you can support us, visit www.parkinson.bc.ca/donate.

SUPPORT GROUPS

Our network of over 50 volunteer-led support groups provide people with Parkinson's, and their caregivers and families, an opportunity to meet in a friendly, supportive setting. For our full support group listings, visit www.parkinson.bc.ca/groups.

100 Mile House, Abbotsford, Bereavement, Burnaby, Campbell River, Carepartner Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Duncan/Cowichan Valley, Gabriola Island, Kamloops, Kelowna, Kelowna Carepartners, Kelowna West, Kootenay Lake East Shore, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Carepartners, New Diagnosis, New Westminster, North Shore, Osoyoos/Oliver, Parkinson's Online, Parksville/Qualicum, Parksville/Qualicum Caregivers, Port Alberni, Powell River, Prince George, Quesnel, Richmond, Richmond Carepartners, Sunshine Coast (Sechelt), Surrey, Trail/Castlegar, Tri Cities, Tri Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Carepartners, Vancouver Downtown Working Professionals, Vancouver West Side, Vernon, Vernon Caregivers, West Vancouver Carepartners, White Rock, White Rock Carepartners, Williams Lake, Young Onset Parkinson's Online

EDITORIAL STATEMENT

Articles contained in *Viewpoints* are for information only. Parkinson Society British Columbia does not guarantee nor endorse any product or claim made by an author. In matters of medical treatment or therapy, patients should consult their physicians.

RESEARCH

Integrated Parkinson's Care Network: Pilot testing of the feasibility and impact of an integrated care network for different stages of Parkinson's disease

PROJECT GRANT

$100,000 over 2 years, funded by Parkinson Society British Columbia through the Parkinson Canada Research Program

RESEARCHER

Dr. Deepa Dash

INSTITUTE

Ottawa Hospital Research Institute

As Canada's population ages, more people are living with Parkinson's disease (PD). Given a limited number of neurologists are located mainly in big cities, people will have to manage the symptoms of their chronic and progressive illness between infrequent visits to specialists.

Dr. Deepa Dash, a neurologist, has a two-year clinical fellowship in movement disorders at The Ottawa Hospital and the Ottawa Hospital Research Institute. She's testing the effectiveness of creating an integrated care network for about 50 people in the intermediate stages of PD – between two and eight years after diagnosis.

The network, managed by a nurse who specializes in PD, will connect people to local resources. Working with the nurse, people will identify the top issues that concern them, and develop an individual plan to address those priorities.

"People don't usually think about what their top three priorities are and how they will deal with those problems," says Dash. "Sitting with them and making a plan often helps."

Using a combination of internet and print resources, apps, and community programs like exercise classes or speech therapy, the nurse who is the clinical care integrator will help people with Parkinson's and their family members to enact the plan.

Since PD encompasses a variety of symptoms, Dash expects some people to focus more on cognitive issues, such as anxiety or depression, and others to work on motor symptoms, such as speech, balance, or tremors.

Deepa hopes belonging to the network will improve members' overall health.

"People should be empowered to manage their own health."

Dash is assessing the feasibility of creating and running these networks, which could be enacted across Canada. She's also evaluating their cost-effectiveness.

People newly diagnosed with PD who enrolled in a similar network reported improved perceptions of chronic care, self-management, and health outcomes. Now Dash and her colleagues want to see if the benefits persist for people at the intermediate stage of the disease.

Ultimately, Dash hopes these networks will improve the quality of life for people with PD and their caregivers. She particularly empathizes with caregivers after seeing her aunt struggle to take care of her uncle, who is in the advanced stages of Parkinson's.

Dash was drawn to working with people with Parkinson's because of the complexity of the disease and the opportunity to understand and help manage the spectrum of motor and non-motor symptoms.

"Neurology is very systematic – it's almost like math," she says. "I like the way you deduce a diagnosis."

Originally from Delhi, India, Dash began her medical studies there but moved to Canada for her fellowship. She hopes to get an academic post here.

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ASK AN EXPERT

Dr. Jason Valerio discusses sleep dysfunction and disorders in people with Parkinson's

Dr. Jason Valerio, MD, is a neurologist and sleep specialist at the University of British Columbia (UBC) sleep disorders clinic and a movement disorders specialist at the Pacific Parkinson's Research Centre. He graduated from the University of Ottawa medical school, following completion of a MSc. in Neuroscience. He completed his neurology training at UBC. This was followed by two fellowships, one in sleep medicine at Stanford University and one in movement disorders at UBC, where he now practices. His clinical focus is on Parkinson's disease and sleep related pathologies. He has a special interest and research focus on REM sleep behaviour disorder. In 2016, Dr. Valerio spoke at Parkinson Society BC's Victoria Regional Conference on the interplay between sleep and Parkinson's disease.

How common are sleep disturbances in people with Parkinson's disease?

Sleep pathology is one of the most common non-motor symptoms of Parkinson's disease (PD). Although exact numbers are not known, reports suggest approximately 50% – 70% of people with PD experience a sleep disorder.

Common disorders include insomnia (trouble falling/staying asleep), sleep disordered breathing, circadian rhythm sleep-wake disorders (which impact the timing of sleep), periodic limb movement, and restless leg syndrome. Other disorders often seen in PD are REM sleep behaviour disorder (dream-enacting), vivid nightmares, excessive daytime sleepiness, and sleep maintenance dysfunction due to medication wearing off or disruption from motor symptoms of PD.

What is REM sleep behaviour disorder?

REM sleep behaviour disorder (RBD) is closely associated with PD and other neurodegenerative disorders and can impair quality of sleep for both people with PD and their bed partners. REM or rapid eye movement is a sleep phase in which the body is immobile, often associated with dreaming. In RBD, the paralysis circuit in the brainstem — which should be 'on' during REM sleep — is now disrupted so that people with parkinsonism can act out their dreams instead of remaining still.

Oftentimes, people with PD may not recognize that they have RBD unless injury occurs. Falling out of bed, or striking walls or nightstands may result in injuries, which can be unfortunately common in people with RBD. People who experience RBD also have higher rates of periodic limb movement and nocturnal leg cramping, which can lead to further sleep disruptions. Vivid nightmares also coincide with RBD and infrequently can cause anxiety and distress leading to further sleep dysfunction.

What are some effects Parkinson's can have on sleep quality?

Overnight, people with PD may experience more severe symptoms due to their medications wearing off, or their medication dosage being too low. This can result in stiffness, rigidity, tremors, dystonia, akinesia, pain, and even akathisia-like symptoms (restlessness), all of which can lead to sleep maintenance dysfunction or early-morning awakenings. Bladder issues, which are frequently seen in PD, also result in more trips to the washroom at night, again potentially fragmenting sleep.

When nocturnal sleep begins to be interrupted, as with all the disorders described above, there is a potential for arousals or short awakening periods to become more frequent or longer in duration. This sleep maintenance dysfunction can result in chronic insomnia leading to daytime dysfunction.

How can Parkinson's medications contribute to sleep dysfunction?

Medications, and their impact on sleep and alertness, are a major consideration when deciding on the best pharmacotherapy for each individual. Most people

A good night's sleep is essential for maintaining your overall wellbeing.

with PD are on dopaminergic drugs, which can cause disruptions in sleep and wakefulness. Individuals can experience excessive daytime sleepiness, and even sleep attacks, as adverse effects from dopamine agonists, and less commonly from levodopa. Impulse control disorder, another side effect from dopaminergic drugs, can also result in disruption or continuation of sleep disturbances.

One drug, amantadine, can contribute to insomnia if taken too late in the day. Many antidepressants, used commonly in PD, can also trigger or worsen RBD. Medications to treat hallucinations, such as antipsychotics, tend to be very sedating, again resulting in sleep and wakefulness dysfunction, and if taken at night, a morning 'hangover' effect can be experienced. Benzodiazepines, which are used less commonly nowadays in PD, can be sedating, but also worsen sleep disordered breathing at night.

What characterizes a sleep disorder?

Sleep dysfunction is very common in society and most people will experience some difficulty with sleep in their lifetime. However, to make the distinction with a sleep disorder, the sleep disturbance has to cause clinically significant dysfunction in social, occupational, educational, or other important areas of functioning. For example, many people who are older experience early morning awakenings, and in turn go to bed earlier. This sleep-wake pattern is not considered a pathology unless it is interfering with quality of life, causing distress, or resulting in significant dysfunction to daily activities.

What is circadian rhythm?

All humans have roughly a 24-hour internal clock that guides a vast array of biological functions and behaviours; this is the circadian rhythm. During this 24-hour cycle, varying metabolic processes occur and chemicals are released to guide behaviours including sleep. In the mornings, alerting chemicals kick in, assisting with the "wake up switch" in the brain, and another set of chemicals triggers the "sleep switch" of the brain at night. Light is the most important synchronizing agent controlling the body's circadian rhythm. Although sunlight guides our chronobiology, people may have preferences on an individual level, typically by a couple of hours. This varying chronotype suggests some people are morning types (larks) or evening types (owls) based on their subjective preference.

What are some practical ways to regulate your circadian rhythm?

One of the most important strategies is using sunlight to optimize the circadian rhythm. This means waking up at the same time every day, getting out of bed and exposing yourself to bright light. Going for a walk every morning, or doing other forms of exercise in the sun, can be a great way to regulate the circadian rhythm. In BC, we have reduced sunlight during certain times of the year and during those times a bright light lamp can be used to replicate the sun. Inversely, bright light should be avoided at night; this includes avoiding TVs, computers, and cellphones 60 minutes before bed.

Having a fairly consistent schedule throughout the day with meals, medications, and timing of activity can also help. If a nap is required, 20-30 minutes maximum is suggested between 2pm and 4pm, during which there is natural lull in the circadian rhythm.

CONTINUED ON PAGE 9...

LIVING WELL

Gut health in Parkinson's

The human body contains trillions of bacteria, viruses, and fungi. These living things are called microorganisms, or microbes for short, and they can have a large impact on your health. While some of these microbes can be associated with disease, others are extremely beneficial and crucial to maintaining a healthy immune system and overall well-being. Altogether, the microbes contained in your body may weigh between 2 to 5 pounds – roughly the same weight as the brain (Robertson, 2017).

A diet rich in whole, plant-based foods is ideal for optimal gut health.

A community of microbes contained in any specific part of the body is called a microbiome. The gut microbiome contains the majority of your body's microbes, residing in your large intestine in a pocket called the cecum. Although there are many different types of microbes, the most widely studied are bacteria, with over 1000 different species of bacteria residing in the gut alone (Robertson, 2017). Each species plays a large role in many aspects of health, such as the immune system, digestion and absorption of nutrients, weight, cognition, and heart health. Thus, an imbalance of bacteria in your gut, or a lack of healthy microbes in your system, can contribute to issues like weight gain, poor digestion, high blood sugar, and high cholesterol (Robertson, 2017).

A growing body of research is also exploring the link between gut imbalances to neurodegenerative disorders, like Parkinson's disease (PD) (Silva et al., 2020).

Gut-Brain Communication

Over the last several decades, the link between gut and brain health has become more apparent. Sensations like butterflies in your stomach and "gut feelings" are indications that the gut and brain communicate with each other – this two-way connection is called the gut-brain axis. Experts believe these two organs are closely connected via neurons throughout the nervous system. Neurons are messenger cells that send signals to different areas of your body, including the gut and brain; in fact, the gut alone contains 500 million neurons (Robertson, 2017). Neurons connect the brain and gut through the central nervous system along the vagus nerve, one of the longest cranial nerves in the body.

The digestive system also has its own nervous system, called the enteric nervous system (ENS). The ENS is comprised of millions of nerve cells within the gut that communicate with the sympathetic and parasympathetic nervous systems, but also function independently. Due to this strong connection between the brain and the gut, stress and other negative emotions can affect digestion and gut health, which can then lend to more distress in the brain, ultimately creating an adverse cycle (Dossett, 2019).

Neurotransmitters play an important role in the gut-brain axis. These chemical messengers send signals from one neuron to another, and play a role in maintaining bodily functions, mood, and cognition. A large portion of serotonin – also called the 'happiness hormone' – is produced by gut microbes, as is a neurotransmitter called gamma-aminobutyric acid (GABA), which can reduce feelings of anxiety and depression (Robertson, 2017). Gut microbes also produce other molecules that affect the brain, such as short-chain fatty acids (SCFAs). SCFAs play a role in our brains by maintaining the blood-brain barrier (a protective barrier between blood vessels and other tissues in the brain), reducing appetite, and controlling neuroinflammation. These molecules have been found in lower concentrations within the guts of

people with PD, implicating SCFAs in brain health and neurodegenerative disorders (Guglielmi, 2019).

The gut and brain also communicate through the immune system. Immune cells in your gut regulate how your body responds to illness and injury, while gut microbes control what is passed through the body and excreted. When the immune system is activated for too long, it can lead to inflammation and a breakdown of the gut barrier, allowing harmful toxins that are associated with brain disorders to pass into the blood (Robertson, 2017).

Gut Health & Parkinson's Disease

In 1817, English surgeon James Parkinson reported that people with PD experienced constipation – this is the earliest evidence that imbalances in the gut play a role in Parkinson's (Kwon, 2018). This link has been further established in recent years, with inflammation, irritable bowel syndrome, leaky gut, and altered gut microbiota reported in PD patients years before the onset of motor symptoms (Douglas, 2020).

In Parkinson's, a protein called alpha-synuclein misfolds to form Lewy bodies in the brain, which are clumps of protein that disrupt brain function. Certain research suggests that alpha-synuclein originates in the gut and travels to the brain, and that an increase in intestinal alpha-synuclein can be linked to changes in the gut microbiome, leading to inflammation and gut permeability (Douglas, 2020). People with PD often also have distinct fecal microbiomes when compared with healthy members of their household who share the same diet (Douglas, 2020). The balance of gut flora has also been found to influence the types of pain that people with PD experience (Rajoka et al., 2017).

While more research is necessary to explore these links further, it is believed that the cognitive changes associated with neurodegenerative disorders such as PD may be preceded by, or occur in conjunction with, gastrointestinal disorders. Due to this key role of the gut-brain axis, managing intestinal health may help in both controlling various symptoms and pain associated with PD, and in decreasing the risk of developing PD and other neurodegenerative diseases altogether (Douglas, 2020).

Maintaining your Gut Microbiome

As your microbiome plays such a large role in health and disease prevention, it is beneficial to consider ways you may improve and maintain the balance of bacteria in your gut. Diet is a key way to promote a healthy composition of microbes. For example, individuals who consume high-fiber, low-fat diets are found to have lower levels of disease-causing bacteria and larger amounts of beneficial microbes (Rajoka et al., 2017).

In addition to eating a balanced diet, maintaining good sleep, exercising regularly, and practicing self-care may also help maintain a healthy gut microbiome. Studies suggest that irregular sleeping patterns can negatively impact the balance of gut bacteria, potentially leading to inflammatory diseases – try sticking to a regular sleep schedule with at least eight hours a night (Voigt et. al, 2014). As your gut can also be affected by stress, self-care outlets such as meditation, mindfulness, or journaling, along with physical activity like walking or yoga, can help lower stress levels, optimize gut health, and ultimately prevent disease.

Sources

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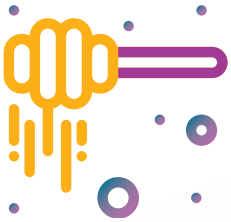
SEE NEXT PAGE FOR NUTRITION TIPS...

NUTRITION TIPS FOR A HEALTHY GUT

A balanced diet is essential for a healthy gut microbiome!

Before you begin, remember to discuss any major dietary adjustments with your doctor.

Include a diverse array of ***high-fiber fruits and vegetables*** in your diet – especially leafy green vegetables, as the fiber in these foods strengthen good bacteria.



Limit simple sugars and artificial sweeteners – they often spike blood sugar levels and can be harmful to good bacteria.

Try eating a more ***plant-based diet*** – vegetarians have been found to have healthier microbiomes containing fewer disease-causing bacteria.

Eat ***pre and probiotic-rich foods***, such as whole grains, apples, onions, garlic, beans and lentils, bananas, and fermented foods like yogurt, kefir, and kimchi.

Foods rich in polyphenols, a plant compound with many health benefits, can help alter gut flora to reduce inflammation. ***Polyphenol-rich foods*** include red wine, dark chocolate, green tea, almonds, and blueberries.

Consider taking a ***probiotic supplement***, but be sure to check with your doctor as there are many different strains of bacteria and it is important to find the right type for you.

Source

Robertson, R. (2016). *10 Ways to Improve Your Gut Bacteria, Based on Science.* Retrieved from https://www.healthline.com/nutrition/improve-gut-bacteria

Additional Resources

Bowel Management Program | https://bit.ly/pdbowel
Managing Gut & Bladder Problems | Article | https://bit.ly/gutandbladder
Food for Thought | Video | https://bit.ly/dietandpd
Nutrition | Helpsheet | https://bit.ly/pdnutrition
Nutrition | Video | bit.ly/nutritionandpd

What is sleep hygiene?

The most practical way of thinking about sleep hygiene is to think of it as a set of habits that are conducive to getting good sleep regularly. Resources to learn more about this that I commonly recommend to individuals include Quiet Your Mind and Get to Sleep by Carney and Manber as well as Cognitive Behavioural Treatment of Insomnia by Perlis et al. Although these resources are directed towards treating insomnia, learning about your sleep and optimizing sleep hygiene are the pillars of beginning to manage any sleep dysfunctions. Sleep hygiene strategies include:

- Sleep only as much as you need to feel refreshed the next day.
- Only go to bed when sleepy, but wake up at the same time every day, 7 days a week.
- Make sure the bedroom is dark, quiet, and a comfortable temperature (typically cooler temperatures improve sleep).
- Avoid excessive fluids in the evening. Do not eat overnight, but also do not go to bed hungry.
- No napping or only short naps during the day – be mindful if it disrupts your night time sleep.
- Exercise regularly.
- Avoid all activities in bed other than sleep or sex.
- Do not take your problems to bed.
- Avoid electronics with bright light, such as cellphones, a minimum of 30 minutes, but preferably 60 minutes, before bed.

What are common treatment options for more specific sleep disorders, such as insomnia, REM Behaviour Disorder (RBD), or Sleep Apnea?

The preferred treatment for insomnia is Cognitive Behavioural Therapy for insomnia (CBTi). This can be done on your own, using some of the books that are referenced at the end of this article, or with the assistance of a trained psychologist. If CBTi fails, sedating medications can be used, but are typically a last resort.

The approach to treat RBD is twofold. First, conservative measures should be taken to ensure bedroom safety for you and your partner. This includes soft padding on the floors, keeping beds close to the ground, removing night stands and other objects could cause damage if struck, and having bed partners sleep in another room, or at minimum, placing a large body pillow between people. The second step is ensuring no medications are worsening RBD. Healthcare professionals may suggest using melatonin and, if required, clonazepam to treat RBD when the patient is a risk to themselves or others.

Sleep apnea management varies depending on severity, with the gold standard being Continuous Positive Airway Pressure (CPAP) therapy, which uses a machine to increase air pressure in the throat to prevent the airway from collapsing. In some cases, oral appliances or positional therapy may provide benefit as well.

Is there anything else you would like to add?

Sleep is vital for a host of human functions including but not limited to memory consolidation, healing and body repair, and clearing out metabolic waste products from the brain. With advancement in our understanding of the importance of sleep, we also recognize the importance of sufficient sleep. Although this varies, most humans should look to get 6-9 hours of sleep each night.

People with parkinsonism have high rates of sleep dysfunction, however, simple adjustments in medication timing, bright light exposure, exercise, and improved sleep hygiene can make a tremendous difference in improving sleep quality and, in turn, improving daytime functioning.

Additional Resources

Quiet Your Mind and Get to Sleep by Drs. Colleen E. Carney & Rachel Manber | https://amzn.to/2NYUHDG

Cognitive Behavioural Treatment of Insomnia by Michael L. Perlis et al. | https://amzn.to/3aUvLX6

Sleep, Fatigue, and Sleep Disorders | Helpsheet | https://bit.ly/pdsleepissues

Sleep in Parkinson's | Presentation | http://bit.ly/pdsleepppt

Dr. Daryl Wile on Fatigue & Sleep Disorders | Video | http://bit.ly/fatigueandsleep

Dr. Jason Valerio on Sleep & Parkinson's | Video | http://bit.ly/pdandsleep

APRIL IS PARKINSON'S AWARENESS MONTH

Pictured:
Larry, Rebecca, & Henry Gifford

THE CAMPAIGN

Every year, Parkinson Society British Columbia dedicates the month of April to raising awareness of the unique experiences of people with Parkinson's, and the needs of our community. April Awareness Month is an opportunity to engage the public in expanding their understanding of Parkinson's and the profound effects it has on the lives of over 13,000 British Columbians living with the disease.

This April, we want to spread the message that Parkinson's is ***more than a tremor***. The disease can affect all aspects of one's life, and there is no cure.

Our 2021 campaign highlights:

- Personal **journeys** shared by people with Parkinson's, their families, and carepartners.
- The importance of **living well with Parkinson's** through self-management, self-reliance, and self-advocacy.
- **Community ties and peer support** bringing together the Parkinson's community in BC.

GET INVOLVED

Let others know that April is Parkinson's Awareness Month, and use the hashtag **#MoreThanATremor** on social media to tell your story.

Be sure to follow the Society online, and tag us in your April Awareness Month posts:
Facebook: @ParkinsonSocietyBritishColumbia
Instagram & Twitter: @ParkinsonsBC

Every journey with PD is unique, and we want to hear about yours. Be an ambassador for our awareness efforts and have your story shared in our newsletters, on our website, or in the media. For more information, contact Jovana Vranic, *Marketing & Communications Senior Coordinator,* at jvranic@parkinson.bc.ca.

In this issue of Viewpoints, read two stories submitted to our campaign by Larry Gifford and Leslie Davidson, two British Columbians who are at very different stages of their journeys with Parkinson's disease, but who share the same positive outlook on life.

Larry Gifford was diagnosed with Young Onset Parkinson's disease at just 45 years old. He is the host of a podcast called *When Life Gives You Parkinson's*, and juggles a busy career in media with his active family life and Parkinson's advocacy work.

Leslie Davidson is a retired school teacher and award-winning writer, who channels her talents into chronicling her emotional journey with Parkinson's, and as a carepartner to her late husband, Lincoln, who lived with young onset dementia.

#MoreThanATremor

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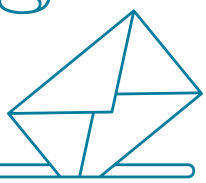
Parkinson Society British Columbia

Letters to Our Younger Selves



Every journey with Parkinson's is unique. The disease can run in families, or come as a complete surprise. Often, many people with Parkinson's don't understand much about the disease until they themselves are diagnosed.

In honour of Parkinson's Awareness Month this April, we are inviting our members to share their journeys by submitting a letter written to their younger selves. These stories serve to inspire hope, spread awareness, and empower others.

Leslie Davidson

Dear Younger Self,

I remember you.

I remember a beautiful spring day, a neurologist's office and those two words. Parkinson's disease.

Early days, the doctor says. Keep exercising. The medication will help when the time comes.

You leave his office and join your husband in the waiting room. He wanted to come in with you to see the doctor but you said, No.

It's his birthday. His 68th birthday. His sister lived with Parkinson's for almost 30 years and then she died. You've read that Parkinson's doesn't kill you. It seems to you that it can, it does. You fear the sorrow in his face. You think you know how this ends but… listen to me…you don't.

You wait until you are in the car to tell him. You weep and he hugs and you say, Let's go home.

Fifteen minutes later — or maybe it's much longer than that— you realize you are not on the highway to home, but on a strange road, high above the city, looking down on the lake and orchards, from an unfamiliar place.

Where are we? you ask.

I've no idea, he says.

You give your head an ironic shake and cannot help but laugh. It is the first time Parkinson's makes you laugh. It won't be the last.

Laughter is going to get you through this. It lives just the other side of tears and, oh my goodness, there are going to be tears.

I can't tell how you should do it differently. You do the best you can. You have days of self-pity and days of Pollyanna optimism. You resist connecting with other parkies —who wants to join that club?— and in your own time, and just in time, you find them, your wise and funny people, and you feel so much less alone. They hold you up.

You research like crazy and sometimes it makes you crazy, all the new knowledge you never wanted to learn. It makes you crazy, and angry and scared and sad.

And then it makes you powerful. It's power to know that protein and levo-dopa don't mix— to know that all the hiking, skiing, biking, and dancing you'd always loved to do will help you cuddle your grandbabies and kick the soccer ball and roll out the cookie dough and hang on to your marbles. It's power to hold a frail 80 year old's hand and teach her a breathing technique to calm the anxiety that her bewildered husband complains is all in her head.

Of course it is, you tell him. Where else would it be?

And if, as time goes on, you start to feel less powerful, it's okay to take a day or a week to mourn the losses, to say out loud, This is hard.

You don't know how it ends. No one does.

Remember that day? That day you heard the words? You weren't truly lost, just a little turned around. And then you laughed.

So…laugh. Gather your people. Learn what you need to know. Exercise. Feel the feelings. Hold someone's hand. You'll always find your way home.

With love,
Leslie

Larry Gifford

Hey Larry,

I know we are still coming to terms with the Parkinson's news. These first few weeks after diagnosis are full of denial and anxiety. Questions, big and small, never seem to stop swirling around in our head.

What is it? Will it kill me? Am I going to need to quit my job? Are they going to fire me? What next? Why me? How'd this happen? What did I do wrong? Aren't I too young to have Parkinson's? Why did I wait so long to seek help? Will I always have trouble walking? Will I need brain surgery? Will I be a burden to my family? Just how degenerative is degenerative? Thousands of others are yet to find their way in between our ears.

You will answer some of these questions on your own soon enough. Your neurologist and other professionals can answer some of the others. If I know you, and I do, because I am the future you: it will take time, perspective, dreams, hope, a community, and your connection to spirit to resolve the rest.

Take deep breaths. Appreciate your newfound slowness. Learn early on to ask for what we want or need, even if that is a nap in the middle of the workday.

Remember, while we are just becoming aware of this Parkinson's part of our lives, it's not new. Parky has been sharing space in our head for decades.

It is not a setback or a bump in the road. It's our life. Acknowledging, embracing, or owning the diagnosis is not surrender. It's taking the power of the Parkinson's back. Parkinson's has not defined you up to this point and it is not who you are. It is a reality of your life that you must manage with discipline.

We are not alone. Parkinson's is the fastest growing neurological condition in the world. This is the first time we've ever been "trendy."

Be in awe of levodopa. We take a lot of these pills in order to live a fairly normal life.

Laughter is great medicine. Laugh every day. Maybe look for a way to use humour as a healing tool?

Learn to say no without feeling guilty. We are not the same person that people have cast us as in their life story. We were not supposed to be "sick guy." It will take a while for it to sink in for other people. We don't need to meet their expectations of you being "well" or "better" or even be the same dude we were twenty years ago when they knew us best.

Parkinson's can be a gift. Actually, it is a rather crappy gift. By that, I mean I would not wrap it up and give it to anyone. However, despite constantly increasing meds, dyskinesia, cancelled outings, nerve pain, and exhaustion, we are living life more than ever. We are going places we have never gone. We are doing things we have always wanted to do, but never made priority. We also have discovered a new level of love and appreciation for our family and friends. When we ultimately accept Parkinson's as part of our life, it opened the floodgates of unconditional love that surrounds and supports us. I am certain it has always been there for us. It just was never so crystal clear.

Larry, we are about to meet some of the most caring, passionate, encouraging, supportive, loving people we've ever known. Many will become instant lifelong friends.

Yes, things will change. Time becomes relative. Plans are always "tentative" depending on how we are feeling. Symptoms come and go, ebb and flow, emotions emerge without warning, and tears lead to laughter and back to tears again.

It's okay. We're going to be fine. Believe it. Have hope.

Love,
Me.

SUBMIT A LETTER TO YOUR YOUNGER SELF

Think of when you were first diagnosed, and all of the questions, worries, and emotions you had at the time. What do you know now that you wish you knew then?

We welcome letters from anyone, whether you were recently diagnosed, or living with the disease for decades. Carepartners and family members are also encouraged to participate.

To learn more and submit a letter, visit www.parkinson.bc.ca/letters.

To read more letter submissions from the community, visit www.parkinson.bc.ca/awareness.

COVID-19

Parkinson Society British Columbia COVID-19 Vaccine Statement

***Note:** The information contained in this article is accurate at the time of publishing. Public health guidelines and COVID-19 vaccination rollout details are rapidly changing. For the most up-to-date information, please visit https://bit.ly/COVIDinBC.*

Throughout 2021, COVID-19 vaccines will be made available to all Canadians. The Government of Canada has announced a phased approach to immunization, and high-risk communities have already begun receiving vaccinations to protect those who are most likely to develop complications from the disease. BC is now moving into phase 2 of the COVID-19 Immunization Plan – approximately 400,000 people will be immunized from March to mid-April, including seniors, Indigenous peoples, and people who live and work in independent living.

There are three vaccines authorized for use in Canada, by Pfizer-BioNTech, Moderna, and AstraZeneca. All vaccines have undergone a rigorous review and authorization process, and have been found to be safe and effective against COVID-19.

Since December 2020, the Government of Canada has been working to ensure the effective distribution of these vaccines as quickly as possible. This process is being managed by several major federal authorities part of the COVID-19 Vaccine Task Force, including Public Services and Procurement Canada, the Public Health Agency of Canada (PHAC), Health Canada and Innovation, and Science and Economic Development Canada. Vaccine rollout to Canadians who are not part of priority groups will be managed at a local level by provincial governments.

About the vaccines

Vaccines work by first exposing the immune system to a germ in small amounts, so if the body is exposed to the same germ at later date, it is "armed and ready" to fight it off. Traditionally, the original exposure to the germ was a weakened or inactive version of the targeted germ. With newer vaccines, such as the Pfizer-BioNTech, Moderna, and AstraZeneca COVID-19 vaccines, the body is exposed not to a weakened germ, but to a specific type of mRNA. The mRNA instructs cells to produce a particular protein, which in the case of the COVID-19 vaccines, is a protein found on the surface of the coronavirus that causes COVID-19. Thus, when you are injected with a COVID-19 vaccine, your cells will produce this coronavirus protein in small amounts, which your immune system will immediately recognize as a threat. Your body will then begin to build an immune response by creating antibodies. These antibodies will remain in your body, so if you were to be exposed to the coronavirus after immunization, your body would know how to defend itself and naturally overcome the disease.

COVID-19 vaccines are administered by a small injection into the muscle of the shoulder. For best results, two doses are necessary. The second dose is given roughly one month after the first, depending on which vaccine you get. You may not be fully protected against COVID-19 until 1-2 weeks after receiving the second dose, so it is important to follow public health guidelines even after receiving the vaccine.

The Pfizer-BioNTech and Moderna COVID-19 vaccines were both found to be roughly 95% effective in preventing COVID-19 1-2 weeks after the second dose. The AstraZeneca vaccine has shown an effectiveness of about 62% in preventing symptomatic COVID-19 2 weeks after the second dose.

Typical side effects of the COVID-19 vaccines are minimal, and do not pose any health risk. These may include pain at the injection site, body chills, fatigue, and mild fever. With any vaccine, there is a rare possibility of allergic reaction and other immune responses. Vaccines, like other treatments, must weigh the risks of getting the vaccine (minimal) vs. the risk of not getting the vaccine the potential for developing COVID-19. Speak to your doctor about any serious allergies or concerns you may have before being vaccinated.

Vaccine Rollout

Vaccines will be made available to subsets of the population in a phased approach to prioritize the immunization of those who are at highest risk of disease complications and death, as well as those in communities who have seen the highest rates of COVID-19 cases. You will not become ineligible to get

the vaccine when a new phase starts – for example, if you are eligible in phase 2, you can still receive the vaccine in phase 3 or 4.

In the current second phase of vaccine rollout, February to April 2021, the following communities are eligible for immunization in BC:

- residents, staff, and essential visitors of assisted living and long-term care facilities
- hospital staff, general practitioners, medical specialists, and healthcare workers with direct patient contact, including community home support workers and seniors' nursing services
- adults in Indigenous communities
- residents and staff of select congregated settings (eg. homeless shelters, correctional facilities, and housing for migrant workers)
- seniors aged 80 and older (born in 1941 or earlier)

Beginning March 8, call-ins will be required to book a vaccine appointment for seniors and adults in Indigenous communities. For seniors born in 1931 or earlier (90+) and Indigenous peoples born in 1956 or earlier (65+), please call the week of March 8; for seniors born in 1936 or earlier (85+), please call the week of March 15; and for seniors born in 1941 or earlier (80+), please call the week of March 22. When calling your local health authority to make a vaccine appointment, you will be asked for your full name, date of birth, postal code, Personal Health Number, and contact information. Call centres will be open seven days a week from 7:00am to 7:00pm. To find out which health authority you live in, visit http://bit.ly/healthauthorities.

QUESTIONS ABOUT COVID-19 VACCINATION?

Speak to your healthcare team about any concerns you may have around immunization, side effects, or your safety amidst the COVID-19 pandemic. If you are unsure about your eligibilty for vaccination, your primary care provider can help you better understand the different phases of BC's vaccine rollout plan, and advocate for earlier immunization if your condition qualifies.

Once priority populations are extensively immunized and additional supply is secured, vaccines will be made available to all other Canadians. From April to June, seniors under 80 will begin to receive vaccines in BC. During this time, younger individuals (under 70) may also be considered for early immunization if they live with a medical condition that puts them at a higher risk for complications from COVID-19. Front-line workers, and employees of certain workplaces and industries may also be included in this rollout phase, depending on vaccine supply.

Following these priority groups, people aged 59 to 18 will be immunized in age-based cohorts from July to September, starting with those aged 59 to 55, and continuing in five-year increments. ***Note:*** Indigenous peoples (First Nations, Métis, and Inuit) are eligible to receive their vaccine with 15-year-older age cohorts. For example, if you are 40 years old, you can get vaccinated in the 59 to 55 age increment.

To accommodate all British Columbians eligible for vaccination, 172 communities across the province will host immunization clinics at school gyms, sports arenas, convention centres, and community halls. Mobile clinics will also be available in some rural communities, as well as for those who are home-bound due to mobility issues. These clinics will be managed by local health authorities. More information will be available before phase 3 of BC's Immunization Plan.

BC is working to create a registration and record system to process vaccine access and provide official immunization records for COVID-19. British Columbians in phase 3 and 4 will register for a vaccine appointment through HealthConnect, a simple online registration system, or by phone. Registration will open in late March, and more details will be made available at that time.

British Columbians will be contacted when it is their time to register for immunization. To make a vaccine appointment, you will be asked to complete a pre-screening and select a location, date, and time online or over the phone.
On the day of your appointment, you should arrive a few minutes early to complete the check-in process, which may vary from clinic to clinic. Once you get your vaccine dose, you will be asked to wait about 15 minutes before departing, so that healthcare staff may observe you in the rare case that you experience any potential allergic reactions or negative side effects. When it is time to book a follow-up appointment for your second dose, you will again be contacted by email, text message, or phone call.

After receiving the vaccine, individual immunization records will be stored in an online provincial database accessible to you and your healthcare team, as well as public health workers. You will also receive a paper and/or digital copy of your immunization chart.

Everyone who is recommended to receive a vaccine will be given the opportunity by the end of 2021. The vaccine rollout schedule for priority groups may be amended over time as disease transmission is monitored, and future vaccine availability in the spring and summer will likely be offered on a priority basis which has yet to be announced.

Those who are vaccinated against the disease are not only protecting themselves, but also everyone around them. Distributing vaccines through priority access helps stop the spread of COVID-19 in areas of the population that are responsible for a majority of cases. Once these groups are immunized, the chance of catching the coronavirus drops for everyone. This concept is referred to as herd immunity. The Government of BC reports that once 60-70% of British Columbians are vaccinated, herd immunity could be achieved.

COVID-19 Safety

Until herd immunity is reached in BC, it is important to abide by public health orders, even if you are vaccinated. Remember to wash your hands regularly, stay home when you are sick, wear a mask in public spaces, and practice physical distancing by maintaining 2 metres of distance from those outside of your household.

Current COVID-19 safety guidelines for BC can be found at http://bit.ly/covidsafetybc.

Considerations for people with Parkinson's

The COVID-19 vaccine is safe for people with Parkinson's disease, their families, and carepartners. mRNA vaccines do not interact with functions of the body that are impacted by Parkinson's disease and other movement disorders, and should not have any interaction with PD medications. Side effects reported in people with Parkinson's who participated in clinical trials for these vaccines were no different than those of people without the disease.

Once people with Parkinson's become immunized in large numbers in the initial phases of vaccine rollout, more data will be available on the effects of the COVID-19 vaccine.

People with Parkinson's in BC are currently not eligible to receive the COVID-19 vaccine early unless they fall into one of the high-risk populations or age cohorts outlined in the provincial vaccine rollout plan. Parkinson's, on its own, does not put individuals at higher risk of catching the coronavirus or developing significant complications from COVID-19. However, those living with other conditions alongside their Parkinson's — such as cancer, heart disease, respiratory conditions, immunodeficiencies, and chronic kidney conditions — may be able to receive the vaccine early during the April – June rollout.

If you are under 70, but experience advanced Parkinson's symptoms with no other co-morbid conditions, speak to your healthcare team about earlier immunization. Those with significant respiratory issues are at higher risk of complications from COVID-19, and may possibly be eligible for vaccination early this summer. More information on eligibility will be available in the coming months.

Learn more

Coronavirus disease (COVID-19) vaccines: Overview | Government of Canada | http://bit.ly/canadavaccines

Pfizer-BioNTech COVID-19 vaccine: What you should know | Government of Canada | http://bit.ly/pfizercovid

Moderna COVID-19 vaccine: What you should know | Government of Canada | http://bit.ly/modernacovid

AstraZeneca COVID-19 vaccine: What you should know | Government of Canada | http://bit.ly/astrazenecacovid

COVID-19 vaccines in BC | https://www2.gov.bc.ca/gov/content/covid-19/vaccine/plan

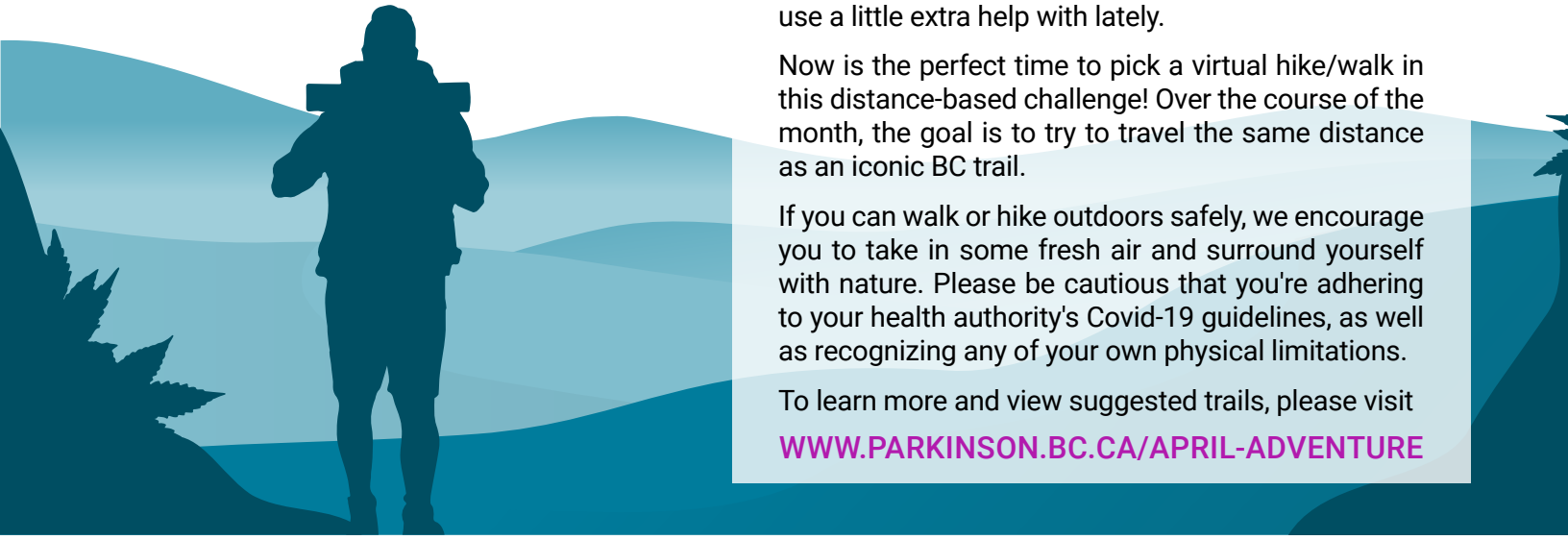
BC's response to COVID-19 | https://bit.ly/covidinbc

Safety and Efficacy of the BNT162b2 mRNA Covid-19 Vaccine | New England Journal of Medicine | https://www.nejm.org/doi/full/10.1056/NEJMoa2034577

An mRNA Vaccine against SARS-CoV-2 - Preliminary Report | New England Journal of Medicine | https://www.nejm.org/doi/10.1056/NEJMoa2022483

CHOOSE YOUR OWN

APRIL ADVENTURE



This spring, Parkinson Society BC is challenging you to ***Choose Your Own April Adventure***.

While we've all been staying closer to home lately, with warmer and more predictable weather ahead, you may be looking for opportunities to get active. Exercise is a great way to manage Parkinson's symptoms, as well as reduce anxiety and stress — which we can all use a little extra help with lately.

Now is the perfect time to pick a virtual hike/walk in this distance-based challenge! Over the course of the month, the goal is to try to travel the same distance as an iconic BC trail.

If you can walk or hike outdoors safely, we encourage you to take in some fresh air and surround yourself with nature. Please be cautious that you're adhering to your health authority's Covid-19 guidelines, as well as recognizing any of your own physical limitations.

To learn more and view suggested trails, please visit

WWW.PARKINSON.BC.CA/APRIL-ADVENTURE

NEWSWORTHY

UPCOMING EXERCISE CLASSES

April Challenger

Let's get moving! Kick-start Parkinson's Awareness Month with the April Challenger! Join PSBC's Shelly Yu, neuro physiotherapist, as she leads you through a fast-paced exercise series aimed at challenging your balance and coordination. Although this class is primarily a standing class, seated modifications will be given to be inclusive of all mobility levels.

Equipment needed for these classes includes:

- a small cushion or pillow
- two light-weight scarves or cloths

Dates:	Thursdays, April 1 - 22
Time:	1:30pm - 2:30pm PST
Capacity:	500
Cost:	Free

Chair Yoga

Join Sheron Jutila as she brings a 4-week series of Hatha Yoga and Joint Freeing practices. The classes begin with breathing practices and body scans, followed by guided relaxation and calming practices, with stretching and strengthening poses. The class can be experienced sitting or standing using a chair as support. Options and variations will be offered so you can explore poses within your current range of motion and level of energy.

Equipment needed for these classes includes:

- a chair, preferably without armrests, and with no wheels (including locking wheels)
- other props, for stability or comfort, will be discussed as needed

Dates:	Thursdays, May 6 - 27
Time:	1:30pm - 2:30pm PST
Capacity:	500
Cost:	Free

UPCOMING ACTIVITIES

Mindful Moments

Join Parkinson Society BC's clinical counsellor, Courtney Doherty, as she leads you in mindfulness practice to help boost brain health, and calm your mind and body.

During this eight-week series, experience mindful moments through mindfulness practice and guided relaxation techniques. With regular practice, positive results can include stress and pain reduction, improved self-awareness, and enriched interpersonal relationships.

Dates:	Tuesdays, April 13 - June 1
Time:	11:00am - 11:45am PST
Capacity:	100
Cost:	Free

Improv for Parkinson's: Laughter is the Best Medicine

This course is designed to introduce students with Parkinson's disease (PD) to the foundations of improvisation and apply improv skills to life with PD. Participants will build community, learn new skills, work together, tell stories, and laugh!

We encourage family members and carepartners to attend with participants, as many games can be played at home after the class. No previous improv experience necessary.

Please note that registration for "Laughter is the best medicine" will be prioritized to those who have not participated in improv classes before.

Dates:	Wednesdays, April 14 - May 19
Time:	11:00am - 12:00pm PST
Capacity:	12
Cost:	Free

TO VIEW OUR FULL EDUCATION EVENT LISTINGS & REGISTER ONLINE, VISIT **WWW.PARKINSON.BC.CA/EVENTS**

SongShine with Sharon

Join Sharon Tomczyk, singer, songwriter, and vocal instructor from Esteem Vocals, as she facilitates our spring SongShine series! Sharon will lead you through the SongShine program which is intended for those whose speech may be compromised due to Parkinson's. These six online classes focus on body awareness, relaxation, and breath exercises, and vocal and singing activities to strengthen voices. Songs are progressively added throughout the six classes as attendees' comfort levels increase. SongShine provides great opportunities to improve your voice, create connection, and lift spirits.

Dates:	Thursdays, April 15 - May 20
Time:	11:30am - 12:30pm PST
Capacity:	50
Cost:	Free

UPCOMING EDUCATION EVENTS

Our Journey: Living with Parkinson's

As part of Parkinson's Awareness Month, join this special online panel event as four presenters who have lived with PD share their stories of hardship and triumph. Our panel speakers are:

- ***Mike Scales***, newly diagnosed
- ***Gina Lupino***, living with Young Onset PD
- ***Debbie Hartley***, living well with PD for 8 years
- ***Karen Dellow***, past carepartner

Every journey with Parkinson's is unique, but many will relate to the emotions that come with navigating its ups and downs. Hearing stories from those who have endured similar challenges may help empower you to overcome your own. This webinar will also feature a question and answer period. People with Parkinson's, carepartners, and families are all welcome to attend.

Date:	Wednesday, April 14
Time:	11:00am - 12:00pm PST
Capacity:	500
Cost:	Free

RENEW YOUR MEMBERSHIP

Members of Parkinson Society British Columbia are part of a friendly, caring, and supportive community. Sign up or renew today for only ***$25***, and you will receive an annual membership for you and your household, valid until December 31, 2021. Reasons to renew your membership:

Stay informed. Get the latest information on a wide variety of Parkinson's-related topics when you receive our quarterly magazine, Viewpoints, and other publications.

Be heard. Vote at our Annual General Meeting and add your voice to the community to garner support from donors, sponsors, and politicians. There is strength in numbers — every membership helps us grow our Society's impact.

To sign up or renew online today, visit:
WWW.PARKINSON.BC.CA/MEMBERSHIP

Questions? Contact Susan Atkinson, *Donor & Member Services Coordinator* at 1-800-668-3330 ext. 263 or email satkinson@parkinson.bc.ca

Thank you to our fundraisers & donors!

Donate a Car

In 2020, the Donate a Car program brought in $985. Thank you to all those that chose to donate their car to benefit Parkinson Society BC!

CORRECTION

In our Winter 2020 issue of Viewpoints, there was an error in team recognition for Parkinson SuperWalk. We wish to acknowledge the ongoing support of team Good Vibrations in Kelowna, BC, who raised $16,130 last year.

Save the Date

Parkinson SuperWalk returns virtually this September. Registration opens in early May!

Parkinson SuperWalk is Parkinson Society British Columbia's largest annual fundraising event. Funds raised through SuperWalk help us provide life-changing programs and services to our community. During the COVID-19 pandemic, we have made strides to ensure that the people with Parkinson's, carepartners, and families get the support and resources they need in this difficult time.

Fundraising through SuperWalk is crucial to the Society as we move forward with adapting to the new normal.

Gather your teammates, save the date, and join us at the 31st annual SuperWalk!

Parkinson SuperWalk in British Columbia is operated by Parkinson Society British Columbia under license from Parkinson Canada.

Questions? Call or email Caroline Wiggins, Special Events & Fundraising Officer
604-662-3240 ext. 255 | 1-800-668-3330 ext. 255 | cwiggins@parkinson.bc.ca

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